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"Autism is me": an investigation of how autistic individuals make sense of autism and stigma

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ABSTRACT

There are many different perspectives for understanding autism. These perspectives may each convey different levels of stigma for autistic individuals. This qualitative study aimed to understand how autistic individuals make sense of their own autism and experience the stigma attached to autism. The study used critical grounded theory tools. Participants (N=20) discussed autism as central to their identity, and integral to who they are. While participants thought of autism as value neutral, they expressed how society confers negative meanings onto autism, and thus, them. The findings also indicate that different understandings of autism confer different levels of stigma. Participants expressed constant exposure to stigma and managed this stigma in different ways. Such methods included reframing to more positive understandings of autism, the reclamation of language, and using concealment and disclosure strategically. The implications of these findings are discussed further in the article.

ARTICLE HISTORY

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KEYWORDS

Autism; stigma; minority-stress; identity; identity first language

Points of interest

- Autistic research participants consider their autism to be value neutral – akin to any other feature like race or hair colour.
- Participants feel that society sees their autism as being a bad trait to have.
- Participants struggled with the tension in how they see themselves, versus how they believe society sees them.
- Participants are caught between disclosing that they are autistic and concealing it, but feel they are treated negatively either way.
- Participants use the word “autistic” to reclaim autism from stigma, and to reframe peoples understandings of autism to be less negative.

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Introduction

Autism is understood to be a neuro-cognitive condition in which autistic individuals are said to lack the ability to infer the minds of others, struggle to empathise and display extreme male traits (Baron-Cohen et al. 2009). Similarly autism is understood as a “triad of impairments” in which individuals have “impaired social interaction and verbal and non-verbal communication, and repetitive and stereotyped behaviours” (Van Wijngaarden-Cremers et al. 2014). Individuals are described as being on the autistic “spectrum” to reflect the heterogenous nature of autism (Lai et al. 2013). Neither a cause, nor a cure have been found (DeFilippis and Wagner 2016). The most extensive study to date indicates a genetic aetiology (Bai et al., 2019).

Autism has been pathologized as disease or disorder (Evans 2013). However, autistic individuals do not typically understand themselves within a model of pathology (Bagatell 2007; Kapp et al. 2013). These views are often dismissed as autistic individuals are said to lack epistemic authority - that is, the ability to contribute to knowledge formation on autism (Frith and Happe 1999; Hacking 2009a). Indeed, it has been argued that *because* autistic individuals are autistic, they lack the ability to produce reliable knowledge on autism (Frith and Happe 1999; Hens, Robeyns, and Schaubroeck 2019). Different ways of understanding autism convey different levels of stigma, however. Autistic individuals tend to have a reliable and scientific understanding of autism, which is also less stigmatising (Gillespie-Lynch et al. 2017). Thus, this study aims to qualitatively investigate autistic individuals’ identity and how they themselves, consider autism.

The ‘autistic person’, is not a natural category; instead it came into existence as a psychiatric diagnosis (Evans 2013; Hacking 2009b). Autism has developed under technocratic power structures (Evans 2013; Silberman, 2015) wherein the power to define the meaning of autism has been held by non-autistic researchers and medical professionals (Evans 2013). Autism has evolved from a form of mental-illness to a cognitive condition (Chapman 2019; Evans 2013). Although there is currently an emerging focus on ethical, participatory autism research (Fletcher-Watson et al. 2019; Milton et al. 2014), some research on autism has traditionally excluded and dehumanised autistic individuals (for brief reviews see Gernsbacher 2007; Cowen 2009).

While not all research on autism is dehumanizing (for example: Cage, Di Monaco, and Newell 2018a; Crompton, Fletcher-Watson, and Ropar 2019; Kapp et al. 2013), there is still a distinct history of dehumanizing autism research (Cowen 2009). Examples of pathology and dehumanization include conclusions that autistic individuals are an economic burden (Ganz 2006; Lavelle et al. 2014), incapable of having moral-selves, personhood, or community (Barnbaum 2008), are inherently selfish/egocentric (Frith 2004), have integrity equivalent to that of non-human animals (Russell 2012), lack an

ability to infer the minds of others (Baron-Cohen, Leslie, and Frith 1985), are sub-human and in need of rebuilding as “proper humans” (Lovaas, Schaeffer, and Simmons 1965) and “exhibit less marked domesticated traits at the morphological, physiological, and behavioral levels” (Benítez-Burraco, Lattanzi, and Murphy 2016 p.1) which may be interpreted as autistic people being less domesticated than non-autistic individuals. Similarly, unfavourable comparisons to Great Apes (Tomasello et al. 2005), brain-damaged monkeys (Bainbridge 2008), and robots or chimpanzees (Pinker 2002) have been made. Extensive arguments supporting the use of eugenics programmes in autism have been published (Barnbaum 2008; Tantom, 2009), with exceptions being made only for those who are economically-productive, and normative enough to not make others uncomfortable (Tantom 2009, p. 219).

As autism is not a natural category (Hacking 2009b), and instead has derived meaning from non-autistic researchers who hold technocratic power (as it is the case of most psychiatric, and disability labels (Smart 2006)), one should be wary of the consequences of such narratives. These dehumanising narratives may have more influence than recognised, especially when framed as being medical and scientific (Smart 2006). Such perspectives can become pervasive within society, for example, autistic individuals are considered as having less human uniqueness (indicating dehumanisation by non-autistic people) (Cage, Di Monaco, and Newell 2018a). Autistic individuals, and advocates have highlighted the issue of dehumanising rhetoric frequently occurring in autism research, and report feeling alienated by it (Luterman 2019; Rose 2020).

Similarly, media representations (Holton, Farrell, and Fudge 2014; Huws and Jones 2011; Jones and Harwood 2009) and stereotypes of autism (Wood and Freeth 2016) are predominantly negative. Eight of the top ten stereotypes non-autistic people associate with autism are rated negatively (including autistic people as having difficult personalities/behaviour, being withdrawn, and awkward). Similarly, 67% of the media framings of autism in the United States, and Britain over 15 years had stigmatising cues (Holton et al. 2014). In both British (Huws and Jones 2011) and Australian (Jones and Harwood 2009) media, autistic people are portrayed as either dangerous/unstable, or unloved and mistreated. Thin-slice judgements of autistic individuals are more negative than those of neurotypical peers and neurotypical peers are less willing to interact with autistic individuals (Sasson et al. 2017). Both the behaviours related to autism (Sasson et al. 2017), and the label (Ohan, Ellefson, and Corrigan 2015) are stigmatised. These negative framings and perceptions of autistic people can make autistic individuals feel pressure to conceal their status on the spectrum and to camouflage as non-autistic, despite this impacting their mental health (Cage, Di Monaco, and Newell 2018a). This is not to suggest that there are no “positive” framings of autism,

rather that they occur less frequently. Of the top ten stereotypes non-autistic people hold towards autistic people, only two are rated as being positive: “high-intelligence” and “special abilities” (Wood and Freeth 2016). These positively rated framings also occur in media representations of autism, and are associated with Savant-Syndrome (such as Sheldon Cooper, or Rain Man) (Draaisma 2009).

Autistic individuals are more likely to support models of autism acceptance than pathologization (e.g. neurodiversity) (Kapp et al. 2013). Neurodiversity is the concept that autism represents biological diversity in cognitive/neurological function (Singer 2017). A central tenant of neurodiversity is that autism does not necessitate suffering (Jaarsma and Welin 2012; Kapp et al. 2013; Kras 2009). Autistic advocates have continued to push back against strictly negative framings of autism, seeking some form of recognition for a multifaceted autism, in which there are peaks and troughs of ability (Hacking 2009a; Jaarsma and Welin 2012). Despite neurodiversity being framed as a rose-tinted view of autism, those who endorse it are more likely to have a balanced view of autism compared to those who supported pathologizing autism (Kapp et al. 2013). The arguments of neurodiversity, to some degree, align with the theory of autism as another “form of life” (Chapman 2019; Hacking 2009a). Form of life theory argues that autism constitutes a different form of life, rather than being a deficit of mind. That is, one cannot refer to a disorder based on an autistic inability to understand neurotypical brains, as neurotypical individuals similarly fail to read autistic states of mind, and rate them unfavourably based on reduced readability (Alkhaldi, Sheppard, and Mitchell 2019). This has been named the double-empathy problem (Milton et al. 2014).

To date, little research has been conducted on the sense-making or narratives autistic individuals have in navigating these different perspectives of autism, nor how autistic individuals understand their own autism (Bagatell 2007, 2010). Thus, the aim of this interview-based qualitative study is to use grounded theory tools to investigate what autistic people consider their autism to be, their experience of autism, and notions of autism versus neurotypicality. It should be noted that in line with the preference of autistic people, this article uses identity first language (autistic individual), instead of person-first language (Kapp et al. 2013; Kenny et al. 2016).

Method

Critical grounded theory (CGT) tools were used in the present study. Critical grounded theory (also known as critical realist grounded theory) integrates grounded theory with critical realism (Hadley 2019; Hoddy 2019). Critical realism presupposes an objective reality which exists independently of our

interaction with it - however, also that all description of reality is mediated through filter of language, individual meaning, and social context (thus it is impossible to step out of perspectivism) (Bhaskar, 1997; Oliver, 2012). It is not the case that all beliefs are equally as true or false, rather that there can be truer or less true accounts of phenomenon (Oliver, 2012). Critical grounded theory tools are retroductive in nature, in that using them involves abstracting potential mechanistic pathways backwards from experiential data, to relevant objects, structures, and conditions that are thought to make these possible (Hadley 2019; Hoddy 2019). Similarly, CGT attends to individual actions through to social structure (Oliver, 2012). Grounded theory tools are underpinned by a relational standard of benchmarking that holds the researcher accountable to the researched (Charmaz, 2008; Harrison, MacGibbon, and Morton 2001). For a more detailed an explanation of CGT, please see Hadley 2019, Hoddy 2019, and Kempster and Parry 2011.

The use of CGT was central to this research because while the label “autism” may describe an underlying reality, all accounts of it have been shaped by the perspectives of those who delineated it (as described in the work by Evans (2013), and Silberman, (2015)). Further, some understandings of autism may confer *more* stigma (Gillespie-Lynch et al. 2017). To date, we have rarely investigated autistic people own meaning making of the nature of autism (Chapman 2019). The grounded tools employed in this study allow us access to this understanding of autism at an individual level by being situated and immersed in the data (a key benefit of grounded theory tools (Oliver, 2012)), while the critical realist application of these tools allow us to bring these individual accounts back into a wider social context of autism.

Reflexive journaling

Reflexive journaling (Janesick 2015; Ortlipp 2008) was used throughout the process. Reflexive journaling helped the researchers to make sense of our epistemic responsibility for the knowledge we produced. Epistemic responsibility refers to a process of taking responsibility for the impact of ones’ research, and for the implications of making interpretations from data (Barad 2007; Teo 2010). Reflexive journaling was used as a tool for understanding how characteristics of the researchers might have influenced the perception of participants and their experiences, and to provide a log for retrospection (Ortlipp 2008). These logs were used throughout the process of data collection and analysis to increase the transparency of the process given that understanding of phenomena is shaped by perspective (Bhaskar, 1997). Furthermore, they were also used to keep track of how the researchers’ perceptions of the data changed over time.

Recruitment process

Ethical approval was gained before recruitment. Anonymity of participants was ensured. The only participation incentive offered was entry into a prize-draw. Participants had to consider themselves autistic (both diagnosed and self-diagnosed participants were welcome to participate), be 18 years of age and have proficiency in English to participate. Participants were recruited both online and locally at the University of Surrey. Posters and digital posters were used for recruitment. Moderators of autism-based online groups were contacted to ask for permission to advertise in groups. Participants were involved worldwide because autism and how it is understood can be a culturally situated phenomenon (O'Dell et al. 2016), and the aim of the original study was to understand a more shared perspective of autistic community connectedness (we aimed for perspectives beyond a British sample). People emailed the lead researcher to participate and were sent participant information sheets. If they still wanted to participate a date/time/method of interviewing was chosen. Methods of interviewing included face-to-face, online using audio-video software, or a text-based interview (including email interview). At the beginning of the interview the participant information sheet was given to the participant for a second time before they received a consent form to sign (manually or electronically). Participants who consented continued in the study. Participants could consent for their data to be used in this study alone, or also in secondary analysis.

Sampling method

This study used purposive theoretical sampling. Theoretical sampling is an evolving method of sampling (Corbin & Strauss, 2008). Data are analysed throughout data collection and guide who should be included in the sample next. This was important for the study at hand, as the autistic community is heterogeneous and contains individuals with a wide range of communicative needs. Original methods of data collection included online audio interviews, and face-to-face interviews (twelve participants were recruited). Enquires were made by individuals who wanted to take part but would struggle with these methods. These participants did not communicate verbally, and so neither the face-to-face nor online audio interviews would work. An amendment to the methods was made to allow for a broader range of participants (an amendment to ethical review was submitted and accepted prior to changing methods of data collection). During the second stage of collection, participants could also take part via email interview that would not require the social aspects of audio or face-to-face interviews.

Participants

Twenty-two people expressed interest in participating. Two participants declined after requesting more information. One such participant withdrew after reading the participant sheet (they had concerns it might be distressing). Twenty participants were recruited for the study. Ages of participants ranged from 21-62 ($Mean = 37.2$, $SD = 13.1$). Nine participants were men, nine women, and two were non-binary. Twelve participants had a diagnosis of Asperger syndrome, three participants had a diagnosis of autistic spectrum disorders/pervasive developmental delay, one participant was undergoing assessment, and four suspected they were autistic. Thirteen participants were White British, one participant was Black British, five were White other from Europe, America, Israel or New Zealand, and one participant was mixed-race South American. Thirteen participants were heterosexual, four participants were bisexual, one participant was pansexual, and two participants left their sexuality undisclosed.

Interview method

Face-to-face interviews occurred at the University of Surrey ($n = 9$). Online interviews were conducted over 'ClickMeeting' via either audio ($n = 8$) or a text-message system ($n = 1$), and email ($n = 2$). Audio and face-to-face interviews were audio-recorded to allow for transcription later. For anonymity, only the participant and lead researcher were present at each interview. The duration of the interview varied (32-92 min, (Total = 15.53 h, $Mean = 44.23$)), (excluding three text-based interviews). Face-to-face interviews were held in one location as all the researchers were based there and did not have the means to interview a global sample in person.

As part of the data collection and analysis method, constant comparative methods (Corbin & Strauss, 2008; Kolb 2012) were used. This means that data were analysed from the point of collection, compared to other data collected, compared to the questions which were asked, and the current framework being developed. If data were emerging from multiple participants that were not reflected in the interview schedule, relevant questions were added. If emerging data did not fit within the framework being developed, the framework was reworked to remain grounded in the data.

The initial interview schedule evolved from the first interview to the last, being led what participants discussed. The original interview schedule covered three main topics: diagnosis, identity, and community. The project at the time was to investigate autistic community connectedness (Botha et al., n.d.). The study has been separated into two papers – one on stigma and identity, and the other on autistic community connectedness. Stigma was so pervasive that regardless of the topic being discussed, participants often

related it back to stigma. This was done to give enough depth and detail in each paper, as the data were rich and informative.

Questions were added through the process above. The added questions included questions about stereotypes of autism, how society perceives autism, and whether participants could tell when someone else they were interacting with was autistic. Stigma was the main topic which was not asked about in the original interview schedule, but which became apparent from the data. Prompts were used where a participant had short answers.

Data analysis

Nvivo 10 and 11, were used to manage and analyze the data. The coding was done by the first author, which allowed for continuity between interviewing, coding, and analysis, across participants. In presenting the data below, names and identifying information have been changed for anonymity. All direct quotations have information for traceability. Coding was carried out according to grounded theory techniques. This means open coding, axial coding, and selective coding (Hoddy 2019). The coding process was iterative and non-linear. During open coding, each interview was coded line by line, according to people's understandings of what they are doing and their reasons (Hoddy 2019). All transcripts were coded line by line, meaning no information was considered surplus. Tentative links were posited between participants and open codes.

Once more than three participants had been interviewed, axial coding began. Axial coding includes noticing regularities in data between participants and how they discuss events (Charmaz 2006; Corbin & Strauss, 2008; Hoddy 2019). Axial coding aims to understand the relationship between categories created in open coding. The researcher tries to notice the context in which a category exists. This is a stage of abduction (Hoddy 2019). Possible mechanisms are described. Open coding continues alongside axial coding.

During selective coding, core categories are selected and highlighted (Hoddy 2019; Kempster and Parry 2011). The relationships these core categories hold with other categories are highlighted. The data at this point are abstracted upwards into theory, related to areas of literature, and compared to other research (Hoddy 2019). This is where there is a concretisation of data and their place amongst other research and theory.

Results

Summary of overall findings

Core categories discerned were identity, and stigma. In terms of identity, participants made clear, a perceived distinction between autistic individuals and

non-autistic individuals - that is, one could either be autistic or not. Participants described a tension between their own view of autism and society's and described this tension as burdensome. Participants felt that autism was value-neutral, akin to race, sexuality, or handedness, but that wider society considers it a 'bad' trait. Participants expressed being caught in a double bind, recognizing that both disclosure and failure to disclose resulted in negative consequences. Participants expressed the importance of their autistic identity, stating that even if autism is not central to their self-perception, it affects their entire perception of the world. Much of the stigma management discussed by participants involved effects on their identity.

Participants discussed how they experienced stigma, infantilization, discrimination, dehumanization and powerlessness. Stigma related to gendered stereotypes of autism, assumed incompetency, and violence. Participants described stigma and stereotypes as limiting, and destructive. Participants detailed how these effects were experienced from childhood, regardless of diagnoses, and resulted in complex stigma management. Stigma management included concealment and attempts to fit in, strategic disclosure, reclamation of language and identity, and attempts to change the social meaning of autism through reframing.

Identity and autism

Participants spoke about what their autism meant to them. These discussions were framed around identity. This section will discuss how participants discussed autism, and identity. Participants' views on this were surprisingly homogenous. The way participants described their experience of autism became an important backdrop for the later discussions of stigma.

All participants made clear arguments for autism as a biological, value-neutral, internal reality in which autism was inseparable from who they are:

"Autism is me" - (Emma, 40, White, female, seeking diagnosis).

"It is very much a core part of my identity because it affects everything... without it I would be so completely different, you cannot separate it from me"-(Polly, 32, female, White, British, diagnosed)

"Autism makes me who I am. Yes, autism is an integral part of who I am. It affects the way I think, communicate and socialise." - (Carley, 21, female, White, British, diagnosed).

All participants argued that one could either be autistic, or non-autistic and that although autism itself was a spectrum, humanity was not a spectrum between non-autistic and autistic (i.e. not everyone is a "little autistic"). This is epitomised in the following quotes:

"You often get people... who might be described as neurotypical who would take some typical Asperger symptoms and say oh yes we all feel like that sometimes or we are all on the spectrum at some point, and I do not agree with that... there is definitely a marked difference between people who have some type of autism and people who do not"- (Michael, 55, white, British, male, married, diagnosed).

"I do not like the "autism spectrum" term because it invites people to say "oh, are not we all a bit autistic"." (Olga, 55, White, female, diagnosis pending).

Most participants described autism as value-neutral, akin to height, skin colour, and handedness, asserting that any value attributed is that of society rather than of autism itself. Similarly, it was not a disease or a disorder. The following quotes show how participants considered autism as value-neutral:

"Being autistic is a person's feature, just like being tall, or short, or left-handed, or talented, or deaf, or blind, or dyslexic." - (Abraham, 47, Israeli, male, diagnosed)

"Autism is not a disease; it's just a different brain wiring." - (Polly, 32, White British, female, diagnosed)

"I just think... I think neurotypical people are just typical rather than healthy. They do not see autistic people as being just on a different tack, it sees us as being wrong". (Michael, 55, White British, male, diagnosed).

Most participants describe being acutely aware of their difference from neurotypical people from as early as they can remember (i.e. it did not come with diagnoses or labelling) diagnoses instead provided a positive avenue for identity. Regardless of this positive identity, a certain amount of internalisation of external stigma appeared throughout participants narratives, with participants describing themselves as "weird":

"I mean, my entire life I've been "weird". And I've never been someone who kind of fitted in. Because, I have always been that, you know, square peg in the round hole." - (Emma, 40, White British, female, seeking diagnosis).

"Because until [being diagnosed] I viewed myself as a misfit, a retarded genius, an eccentric, a freak. I saw no future for myself anywhere. The spectrum gave me a new identity, which I view as mostly a positive identity" - (May, 35, White British, female, diagnosed).

Most participants made clear that there was nothing incompatible between being autistic and achieving personhood or the ability to thrive other than neurotypical expectations. Participants acknowledged that autism could still be a disability, but that this did not limit their capacity for a good life necessarily:

"Autistic people have the same potential for life as any other embryo or child" - (Ami, 22, White British, Female, diagnosed).

"The reasons they cite for needing a cure is not [autism] it is that we get bullied or are difficult to 'live' with"- (May, 35, White British, female, diagnosed).

Stereotypes and stigma

When discussing diagnosis, disclosure, discrimination, day to events, childhood, or employment, an apparent underlying theme was stigma. No matter what was being discussed, stigma seemed inescapable. All participants described always being on the outside of the neurotypical world and shunned by society to varying degrees:

"Is it any wonder we are seen as outcasts when society shuns anything marginally different from it?"- (Charlie, 29, gender non-binary, White British, diagnosed).

It is interesting how the participant described society as marginalising anything different in society, as it is not just reflective of ableism, but also applies to a wider minority status which may include non-cisheteronormative gender or sexuality for example, of which autistic people more often are.

There seemed to be an over-whelming awareness that autism is considered an inherently "bad" thing by society. Most participants discussed how the narratives we have around being autistic conveys society's perceptions of it. The quote below demonstrates this sentiment. When asked about how the participant believes society views autism, he inferred stigma from the choice's parents make around vaccination:

"One of the key reasons people choose not to give vaccinations to their babies is they don't want their babies to be autistic... it kind of puts in perspective how people really feel about it. They would rather literally give their child more of a chance of getting a deadly disease than have autism. It really means [autism] is a red card. A cross in the box sort of thing"- (Andrew, 22, Black British, male, diagnosed).

Stereotypes discussed by participants included the association of autism with a complete lack of verbalness, being male, being infantile, or capable of violence. In terms of the stereotype of what an autistic person should look like, participants thought the stereotype was of a White, male, minimally verbal child.

"All they know of autism is it is children, and they don't speak"- (Allison, 57, White British, female, diagnosed).

"A lot of the time autism is associated with cis, het, white males" - (Charlie, 29, gender non-binary, White British, diagnosed).

Participants described being dismissed because they did not fit the content of this stereotype:

[on disclosing to someone] *"You are lying, you can talk ... "* (May, 35, White British, female, diagnosed)

At the extreme, these stereotypes can act as barriers to diagnosis:

"The under-diagnosis of girls on the spectrum, because they defy the stereotypes" - (Abraham, 47, Israeli, male, diagnosed)

"A lot of the time, only boys and men are looked at. Stereotypes have emerged."-
(May, 35, white British, female, diagnosed)

Extreme stigma described by participants was expressed in how autism has been linked to violence. Multiple participants (7 of 20) from different regions of the world discussed their concerns that people associate autism with violence. The two quotes below summarise both this issue and how autism is pathologized in the media:

"[They see us as] troubled minds, who hack into computers and or blow up schools, school shootings... It's rare you hear about autistic adults unless they are the 'dangerous' kind..."- (May, 35, White British, female, diagnosed)

"In news report... [autisms] often described as a disease or a high school shooter... mostly [I feel] annoyed, it's discussed as a disease a disorder and in its more severe additions"- (Michael, 55, White, British, male, diagnosed).

The images of autism and violence provided by participants were usually gendered and referred to school shootings, and how every time a White, man commits an atrocity such as a shooting, the first thing that is talked about is autism.

Stigma management

Understanding stigma in a nuanced fashion involves not only understanding the impact of stigma on marginalized communities but also how those communities cope with such adversity (Goffman 1968). Unidirectional considerations of stigma acknowledge the limiting consequences of stigma; however, fail to acknowledge the communities' ability to resist the impact of stigma. By examining the interaction stigmatized communities have with stigma-related stressors, we can understand what makes the experiences more or less impactful of the lives of those (Frost 2011a). Participants described processes of coping with stigma, such as trying to fit in or assimilate, concealing their autism, and when confident, challenging the stereotype or stigma, showing the relational aspects of autism.

Double binds: Concealment and outness

All participants expressed many situations in which they face "double binds"(Yuksel, Bingol, and Oflaz 2014). For example, participants discussed how they were "damned if they do and damned if they don't" regarding disclosure, because they could tell people, and be judged on the label, or not tell people, and be judged on their behaviour, but either way there were consequences:

"I'm damned if I do and damned if I don't if you know what I mean...I can tell people [I'm autistic] and they think I'm weird and if I don't tell people, they think I'm

weird. When I didn't behave in the way they expected me to - oblique comments were made by staff" – (Allen, 36, degree, New Zealand, White, male, diagnosed).

In terms of concealment participants discussed childhoods where they tried to assimilate, and to make themselves less "different". Most participants described the years in which they had tried and failed to fit in as misspent. Some felt like they had had no childhood at all. The following quote epitomizes the intense pressure autistic individuals felt to assimilate, and how it never worked, making them feel like failures:

"I've spent my adult life trying to assimilate. No matter how I try there are aspects of that I cannot do... mainstream society shuns anything even fractionally different from it... we are told to perform a circus doggy act every single waking moment of our lives. We are told to fit in or die."- (Charlie, 29, gender non-binary, White British, diagnosed).

"I spent my childhood trying and failing to fit in". (May, 35, white British, female, diagnosed).

Participants discussed concealment due to stigma and stereotypes, regardless of age. Concealment and withholding were directly talked about with regards to the stigma imposed on autistic people such as withholding diagnosis because of the worry that people might associate them with violence.

"When I was diagnosed... my kids were still in primary school. I didn't want to turn up at the school gates and have other parents go 'oh yeah that's the guy with Asperger syndrome'... simply because there is so much misunderstanding about what is it... suspicion almost... So yeah, I haven't really come out as someone with Asperger syndrome...you see it all the time in news reports... some high school shooter in the USA who murders his classmates turns out to have Asperger syndrome so I have been very wary about advertising the fact especially around young children, just because I think people might react badly like 'oh we don't want [him] around our kids" (Michael, 55, White, British, male, diagnosed).

It was still the case, even where some participants could see a potential benefit in disclosing, participants had a distinct fear of the response others. The implications this has for receiving support may be important since disclosure is needed for support to be actioned (if necessary):

"I have a dyspraxia diagnosis and I've never disclosed that in the workplace, I imagine I probably could have benefited from doing so, with the autism diagnosis as well. But I am very uncomfortable with other people's perceptions.... There's not a lot of awareness... or positivity... I would be very apprehensive about disclosing"- (Emma, 40, White British female, seeking diagnosis).

Most participants described an unequal dynamic between themselves and neurotypical people when they did disclose. This included erasing of identity through denial, with participants being told: "you are not really autistic". Participants expressed concern that when neurotypical people deny their autisticness they detract from their identity and self, and in turn erase their

experience and needs. It could be a display of power-dynamics between autistic individuals and non-autistic individuals, because again, it removes the self-designation, reduces the meaning of the identity, label, or disability, and then also removes the need for support.

"[when disclosing] people are like, 'well everyone's a bit like that' and it's ridiculous to think that you're really autistic" (Andrew, 22, Black British, male, diagnosed).

Erasing the participant's experiences as being autistic increases the distance between autistic people and neurotypicals by denying the autistic person the space to be themselves. This concept also links with the idea of relying on stereotypes in allowing for identification with the spectrum – in essence, unless you present as a stereotypical image of autism, then you are dismissed.

"It makes me feel bitter and angry when [neurotypical people] do not believe me" (Michael, 55, White British, male, diagnosed).

Reframing and reclamation: Disclosure and language as liberation

Most participants described how language is used to reinforce the place of autistic people in society, and their sub-humanness. Person-first language was described by participant's as a form of control and a reminder that they are not generally considered to be human. This is demonstrated with the following quote:

"It is part of the dehumanization of autistic people – to have to remind neurotypical people we are human. It is condescending for person-first language people to be like remember guys... this is a person in front of you" (Polly, 32, White British, female, diagnosed).

The quote itself lays out a specific power relationship, in which it becomes the duty of autistic individuals to remind non-autistic individuals of their humanity. Similarly, in the act of telling an autistic person to reframe their language to person-first language, it implies a superordinate role for neurotypical people and a subordinate role for autistic people, even for self-identification.

Some participants describe making a challenge to the social hierarchy with language and disclosure as tools of liberation. For example, when peers are having a conversation about autism that reinforces stigma, participants might disclose being autistic in order to challenge the notions of autism being discussed.

"I mean I know that autism gets a big backlash, quite often I find myself in social situations, where I am dealing with someone I don't know too well, who would make a comment, that I think would offend someone on the spectrum and so I will sometimes just say, 'I was diagnosed with Aspergers when I was younger, and I don't

think you should be saying something like that” - (Ami, 22, White British, Female, diagnosed).

Others fantasize about being able to do this but worry about the consequences. This concept of disclosing to unsettle discriminatory views held by non-autistic peers is described well by the following participant when he was asked how he handles situations where he feels he is being treated differently:

“I’ve been tempted to tell people that I am [autistic], but I never have. I think people would be quite surprised that I was autistic and telling them might change how they see autism” - (Michael, 55, White British, male, diagnosed).

Participants seem to choose the language as a reclamation of stigmatized labels, to de-stigmatize them, partly through reinforcing a concept discussed earlier: Autism cannot be separated from the individual. While some participants did not have a strong preference for any particular language, most did, and most preferred identity-first language as the less stigmatizing of the two. No participants preferred person-first language, as all found it in some way demeaning. This related to two things: Firstly, that autism cannot be separated from an autistic individual:

“It is why I never use person-first language – autism is intrinsic to who I am”- (Polly, 32, White British, female, single, diagnosed)

And secondly, autism is not a bad thing and does not need to be separated from the autistic individual:

“saying it as “having autism” is not cool... it sounds like a disease” (Allen 36, White, male, diagnosed)

“using person first language suggests that autism is an inherently bad thing. When you say ‘they have’ it comes under the disease perspective. Like ‘they have cancer... they have MS (multiple sclerosis)’”- (Polly, 32, White British, female, diagnosed).

Discussion

This paper aimed to qualitatively investigate how autistic individuals understand their own autism and the place of autism in society using critical grounded theory tools. The findings give us insight into impact of stigma according to our understanding of autism. Participants believed that autism was value-neutral, and inherent to their existence. Autism was predominantly seen as an important facet of their complicated identities. Participants discussed a tension between how they see autism and how society sees it. Participants discussed stigma and stereotypes as destructive to their identities and lives. Stereotypes associated with autism included autism as a gendered phenomenon, violence, and Whiteness. Participants discussed different methods of stigma management and how and when they employ them.

These were processes of concealment, disclosure, reframing and reclamation. This discussion aims to integrate these findings with research and to highlight the importance of these findings.

Autism is defined by participants as something that affects their interaction with the world, making it something that cannot be separated from them; this narrative is in line with literature autistic advocates publish (Brown 2017). These framings show a close relationship between autism and identity. It similarly gives a narrative explanation as to why autistic individuals tend towards neurodiversity (Kapp et al. 2013). Neurodiversity treats autism as more value-neutral than medicalised models of autism (Jaarsma and Welin 2012).

Participants rejected the idea that suffering was inherent to autism, as some research has hypothesized (Barnbaum 2008; Mikami et al. 2009). Instead, participants described autistic suffering as a product of not being neurotypical in a world that demands it, resulting in isolation, discrimination and victimisation. This gives credence to the idea that autistic individuals constitute a minority group (Walker 2012), and are affected by processes of minority stress (Botha and Frost 2020) and minority-majority group processes (Botha and Frost 2020; Cage, Di Monaco, and Newel, Matthews, Ly, and Goldberg 2015; Sasson et al. 2017). Participants, in expressing the discreteness of neuro-types (being autistic versus non-autistic), acknowledge that they themselves *are* different, but that society marginalizes everything that is different, and this is where the issue lies.

Participants discussed a general sense of stigma existing around autism, but also specific encounters that were stigmatizing. When discussing diagnosis, disclosure, discrimination, day to events, childhood, employment, an apparent underlying theme was a stigma. No matter what was being discussed, stigma seemed inescapable. Traditionally autistic individuals have been described as lacking psychological awareness of 'others' and the self (Williams, 2010). However, the current study shows what appears to be a distinct awareness of participants that they are afforded less space in society, and that they carry a label that society deems unacceptable. One of the clearest images of stigma was how one participant described it as a 'red card' or a 'cross in a box' that separates him from other people, specifically due to how other people construct autism.

The majority of the stereotypes held about autistic individuals are negative (Wood and Freeth 2016). Autistic individuals have reported a sense of feeling trapped by the stereotypes non-autistic people hold of them (Treweek et al. 2019). This was further supported by the data in this study. Participants described a current social hierarchy in which autistic people were subjugated, judged, undervalued and erased. Similarly, participants reported changing their behaviour as a result of stereotypes. This finding is

not unique to this study, being seen even in play scenarios between autistic and non-autistic children, where non-autistic children take leadership roles and express dominance over autistic children (Bauminger et al. 2008).

The most frequently mentioned stereotypes were that autism was a 'male' thing, that autistic people were capable of violence, and of autism as a 'White' disorder. Similarly, participants mentioned frequent stereotypes of autism, such as autistic people being difficult, angry, awkward, and less often a genius (Wood and Freeth 2016). It is interesting that the only time a participant did mention the stereotype of genius, they prefixed it with the term "retarded", juxtaposing a "positively" rated stereotype of autism with a term which heavily stigmatising (Nash et al. 2012). Moreover, that they had internalised these stereotypes to explain themselves, until they had alternative language for their experience (at which point they were no longer these things, but rather, they were autistic).

The concept of autism as "extreme male brain" (Ridley 2018) may contribute to gendered ideas of autism, as it reinforces the idea of autism being or presenting as gendered. However, there is no substantial evidence for brains being biologically constituted for what Baron-Cohen considers "sex-specific" tasks (Krahn and Fenton 2012). A meta-analysis found that for every cis-gendered female in an autism study, there were at least four cis-gendered males (Lai et al. 2012). This research is then used to develop our knowledge and theories of autism, and measures, including creating diagnostics from these predominantly all-male samples. Measures of autism then have become hyposensitive in detecting autism in women (which is a limitation frequently mentioned in papers (Baron-Cohen et al. 2009)). This has become so imbedded in the stereotype and associated autism, that it affects the everyday experiences of autistic individuals.

The "extreme male brain" appears to also shape ideas of autism beyond women and girls. The association between autism and traits which are gendered in society, including violence and aggression are carried forward to their extreme (Krahn and Fenton 2012). Yet, both objective and subjective measures of perpetration of crime are equal between autistic and non-autistic individuals (Im 2016; Weiss and Fardella 2018). By creating the idea of the "extreme male brain", researchers not only further linked autism with an incapacity for empathy, but also reinforced an idea that men cannot empathize to the degree that women can. Similarly, it creates a complicated stereotyped landscape for ethnic minorities to navigate, as violence and aggression are not only gendered concepts, but also typically attached to Black individuals (Wilson, Hugenberg, and Rule 2017).

Participants made clear that they navigated situations of double binds. Participants balanced between whether to disclose (or not), acknowledging that either way they will suffer consequences. Concealment may have

implications as a cognitive burden due to fear of discovery, while outness may result in increased exposure to discrimination (Frost 2011). With regards to autism, these findings are supported by evidence that both the label (Butler and Gillis 2011; Matthews, Ly, and Goldberg 2015) and behaviour (Sasson et al. 2017) of autism are stigmatised. This means regardless of disclosure, participants experience stigma. Furthermore, it is supported by evidence that both concealing (Cage, Di Monaco, and Newell 2018a) and outness (Botha and Frost 2020) have negative implications for mental health in the autistic community. Participants discussed navigating these double binds, in terms of access to support, versus stigma. The weight of stigma appeared to out-weigh the perceived benefits of disclosure resulting in concealment.

The distinction participants drew between being autistic and not (as discrete categories) may have important implication for the ways in which autistic people manage stigma. Stigma theory suggests that where categories are discrete and impermeable, members of socially disadvantaged category will try to elevate the standing of that category (Tajfel and Turner 1979). Thus, the focus becomes elevating the social status of the group (Tajfel and Turner 1979), which is exactly what neurodiversity gives autistic people an avenue towards (Jaarsma and Welin 2012; Kras 2009).

There are concerns that concealment of stigma leaves the stigma unchallenged (Wang et al. 2017). Similarly, by not challenging stigma, it may become internalized or attached to the self (which was identified in the data). It may also be the case that concealment and internalized stigma have a reciprocal relationship. For example, studies have found positive, moderate to large correlations between internalized stigma and concealment in both the concealment of autism (Botha and Frost 2020) and mental illness (Lattanner and Richman 2017).

Reframing and linguistic re-appropriation are both methods of stigma management (Wang et al. 2017) that were discussed by participants. According to labelling theory, being assigned a label can result in the acquisition of stereotyping or stigma as a label infers certain beliefs and behaviours (Link and Phelan 1999). Labels, however, are not static but rather dynamic human creations (Hacking 2006). One could argue that the label of autism has 'accumulated' stigma (Ohan, Ellefson, and Corrigan 2015). In the case of autism, the label was created to give meaning to external behaviours observed in a subset of people by individuals with authoritative voices (Chapman 2019; Evans 2013).

Reframing can be seen on both a community and individual level in these data and in research in general. The neurodiversity perspective relates to a more balanced rather than strictly negative perspective of autism (Kapp et al. 2013). The aim of neurodiversity as a movement similarly, is said to be to shift

researcher and community focus away from a strictly deficit-based model, at a group level. Participants practice a casual reframing through conversations at an individual level; when participants were faced with stigmatizing comments, they either disclosed being autistic, or considered doing so, specifically to show that autism can be a positive identity to reframe how people thought of autism.

Similarly, participants discussed language reclamation (Brontsema 2004). Language that has been used as pejorative based on the specific qualities of a minority community is reclaimed by that community and repurposed to mean something other than character damnation (Brontsema 2004). Reclamation of pejorative terms has been shown to increase feelings of power and weaken the labels stigmatising force (Galinsky et al. 2013). This has happened in the queer community (Brontsema 2004), and the disabled community (Baglieri and Shapiro 2012). Participants discussed reclaiming the term “autistic”, and refusal to bow to the terms that non-autistic individuals thought they should use. Participants rejected person-first language with the argument that they should not be required to remind people of their humanness, and to increase the salience of their autistic identity.

Autistic individuals may be managing stigma by reclaiming language. Considering the unfavourable comparisons that have been made between autistic individuals and animals, robots, or sub-humanness, it makes sense that part of the process of de-stigmatisation includes reclaiming autism and redefining the connotative meaning associated. Participants used identity-first language because they do not consider autism to be negative; thus, it does not need to be separated from them. This process may be important as self-designation results in feelings of increased power, as it has been found in other research (Wang et al. 2017).

Limitations

A key limitation of this study is that the original interview schedule was not made with a focus group of autistic people. It would have been beneficial to begin this process with the input of a group of autistic people. Similarly, the interview schedule was not tailored specifically to the topic at hand (although it adapted with incoming data), as it was originally for a separate project, with questions mainly focused on community connectedness.

A second limitation of the study was the restricted period in which it was carried out as grounded theory studies are time and work intensive. It is hard to do justice to the entire body of data collected in the study and gives the researcher an inordinate amount of power in deciding what is relevant

Lastly, although our methods of data collection were wide and varied, allowing us the opportunity to interview participants who do not communicate in conventional ways, we did not interview anyone who had disclosed a

co-occurring learning disability. Due to the recruitment methods employed in the study, the sample was biased towards autistic people who could read. Furthermore, co-occurring conditions were not screened for, or used as exclusion criteria. Despite some methods of data collection allowing for a spread of participants geographically (by interviewing over internet via email and a text-based message system), the face to face interviews only occurred in one country (England) which may have implications for the results, (having said that, all methods of interviewing yielded similar levels of detail).

Reflection

Reflexive journaling was used a tool to increase self-awareness during the process of data collection, analysis and during creation of this publication. Reflexive notes were made before and after each interview and were referred to. The use of reflexive journaling throughout the process made clear that this research is bourn of a specific context. Elements of insider-outsider status, power, and privilege, all played a role in the construction of the results, and their interpretation. As has been mentioned, the lead researcher for this project is also autistic, meaning a shared identity with participants (referred to as insider status (Perry, Thurston, and Green 2004)). On one hand, this intimate knowledge of the experience of autisticness allowed for a more intimate understanding of what it means to be autistic, which has been described as missing in autism research (Chapman 2019). However, it also means that perhaps a non-autistic lead researcher would have interpreted the data differently. Some participants knew the researcher was autistic (either because of their previous work, or because they enquired), whilst others did not. In order to avoid forced intimacy, the lead researcher only revealed their identity if asked. This was done, as it was a concern that if the lead researcher unduly disclosed their autism that participants would disclose more than they might otherwise.

Reflexive journaling also allowed for me (the lead researcher) to grapple with the power I had in describing the data (as interpretation of data is an action which with consequences (Teo 2010)). Participants also discussed the power that researchers had in autism research, and how there is a tradition of the autistic 'subject'. As such, in the full qualitative project (including this study), every sentence from every participant was coded. This was done to relinquish some of the power that I had as a researcher. It was also done, as reflexive journaling revealed that as lead researcher, I did not relate to each participant in the same way, and as such, it was better to try incorporating everyone's experience, regardless of relatability.

The use of CGT (Hadley 2019) was ideal. Using CGT tools such as theoretical sampling and the constant comparative approach (adding more questions in according to incoming data), allowed us a chance to remain grounded in participant narratives and experiences, as did open coding

“according to people’s understandings of their experiences” (Hoddy 2019). The “critical realist” approach, furthermore, allowed us an understanding of how autistic individuals make meaning from their autism (and how ‘autism’ is filtered through perspective and language), without devolving into a relativist idea of autism. This was particularly important as the original goal of the project was to understand a shared phenomenon (community connectedness), rather than an individual (or relative) experience. Lastly, the concretisation and contextualisation of data within pre-existing literature (a key part of critical realist projects), allowed us to abstract potential mechanisms of how autistic people manage stigma, using language and reframing. This means we abducted from everyone’s own understanding of themselves, and their situation (from open coding), up into the social context of autistic lives.

Directions for future research

More research could be conducted on mechanisms of coping with stigma in the autistic community, such as investigating the effects of different stigma management techniques on mental health, and minority stress in the autistic community. Similarly, group level coping should be further investigated. For example, community as a resource, or community level reframing, like neurodiversity. Finally, more research is needed on linguistic reclamation in the autistic community, as identity-first language is described as less stigmatizing, re-humanizing, and empowering. Research has found reclamation may be a powerful tool (Wang et al. 2017), and it may be similar in this circumstance.

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